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ABSTRACT

This guide is designed to assist family organizations and advocates of children with mental, emotional, or behavior disorders in asking the right questions at the right time during the development of their state's publicly funded managed behavioral health care plans. The first section provides an overview of managed care, including information on how managed care plans operate and how managed care works in the public sector. The second section of the guide provides strategies for family advocates. Specific recommendations are listed under three strategies: 1) be at the table; 2) use materials wisely; and 3) raise critical issues. A detailed glossary of terms used in managed care is provided. A list of relevant reading materials is also included. An appendix provides handouts that can be copied, including an explanation of why special attention needs to be given to designing the system to meet the needs of children and youth, a statement of principles of care for children with serious emotional disturbance, and a statement of principles of family involvement in the development and operation of managed health and mental health care systems. (CR)

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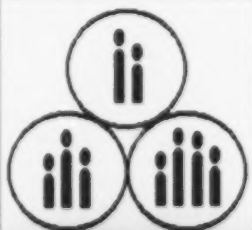
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Managing Behavioral Health Care for Children and Youth

A FAMILY ADVOCATE'S GUIDE

AUGUST 1996



THE FEDERATION OF FAMILIES
FOR
CHILDREN'S MENTAL HEALTH

THE BAZELON CENTER FOR MENTAL HEALTH LAW is the leading national legal advocate for adults and children with mental disabilities. Since its formation as a national nonprofit organization in 1972, the Bazelon Center has successfully challenged many of the barriers to dignity and choice that confront people with mental illness or mental retardation. Our precedent-setting litigation has outlawed abuse in state institutions, won protections against arbitrary confinement and opened up public schools, workplaces, housing and other opportunities for community life. Now, as low-income people across the nation face the loss of federal assistance, we work for access by adults and children with mental or emotional disorders and their families to health and mental health care and other needed services and supports.

THE FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH is a national parent-run organization focused on the needs of children and youth with emotional, behavioral or mental disorders and their families. The Federation's mission is to: provide leadership in the field of children's mental health; address the unique needs of children and youth with emotional, behavioral or mental disorders from birth through transition to adulthood; ensure the rights to full citizenship, support and access to community-based services for children with mental health needs and their families; and provide information and engage in advocacy regarding research, prevention, early intervention, family support, education, transition services and other supports needed by children and youth with emotional, behavioral or mental disorders and their families.

A FAMILY ADVOCATE'S GUIDE was written by Trina W. Osher, Federation of Families, and Chris Koyanagi and Rhoda Schulzinger, Bazelon Center, and designed by Lee Carty, Bazelon Center.

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FOREWORD & ACKNOWLEDGMENTS

Managed care is rapidly becoming the driving force for systems reform in mental health at the state level. However, the special needs of children with mental, emotional and behavioral disorders and their families are not always well addressed in Medicaid and mental health agency plans for managed mental health care. Advocates for children's mental health need to be vigilant as managed care plans are developed in their state.

The Bazelon Center and the Federation of Families urge family organizations and child advocates to join together and use this guide to assist them in asking the right questions at the right time during the development of their state's managed behavioral health care plans. By so doing, they will force public policymakers to address the most critical issues in child services and family support.

A detailed glossary of terms used in managed care appears at the end of this document. When these terms appear in the text without a full explanation, they are highlighted at their first use and defined in marginal notes.

This guide would not have been possible without the comments and ideas of many reviewers. We wish to thank Jane Adams (Keys for Networking, Kansas), Deborah Anderson (S.P.O.K.E.S., Kentucky), Gail Daniels (FASA, Washington D.C.), Kim Delgado (MIKID, Arizona), Patti Derr (Federation of Families for Children's Mental Health, Texas), Hector Mendez (Fiesta Educativa, California), Barbara Sample (Family Support Network, Montana), Teri Sanders (MIKID, Arizona), Elaine Slaton and Mary Telesford (Federation of Families for Children's Mental Health national office), and Velva Spriggs (Center for Mental Health Services) for sharing their perspectives and giving their time to make this document more useful to other family members.

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Chris Koyanagi, Bazelon Center for Mental Health Law
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July 1996

PREFACE

The introduction of managed care for publicly funded mental health services poses a considerable challenge for policymakers. Children's mental health services are provided through a complex system of mental health providers, child welfare agencies, schools and other programs. In too many places, these different agencies fail to collaborate or even to coordinate in providing services and supports to children and their families. Because they have failed to develop a common language, these different systems often have different definitions for terms such as "serious emotional disturbance." The resulting lack of precision impedes good case planning and effective service delivery.

In addition, services for children are generally less available than are mental health services for adults. Even research into the effectiveness of treatments for children lags significantly behind research on adult mental illness, and many child-serving agencies lack understanding about what we do know concerning the causes of and best interventions for mental, emotional and behavioral disorders in children. As a result, these agencies may operate under ill-informed policies that contradict good *treatment protocols* and ignore family values and family support.

In general, families are not seen as partners by the professionals providing services to their child; their unique and extensive expertise concerning their child is largely ignored. Indeed, parents are often blamed for their child's problems and treated as part of the problem. Family strengths are also ignored. For example, many child welfare systems remove children from their families' custody before offering services, and schools, blaming parents for their child's disorder, often fail to provide necessary services until the child is in crisis.

Funding of child and family services is also grossly inadequate. Strategies to pool dollars from various child-serving agencies, while critical for obtaining the maximum resources available, nonetheless mask the unfortunate truth that even the pooled funds fall far short of the need.

In short, in most places the children's mental health system is really a non-system. One of the most dismal consequences is that many of the children left unserved end up in the juvenile justice system—an outcome made more tragic today by the increased emphasis on treating them as adult criminals.

Paradoxically, then, too many agencies duplicate each others' services, yet there is no continuum of appropriate services and very little accountability. There are far too few resources, and those that exist are very poorly directed.

Treatment protocols

—a pre-set pattern to guide clinical decisions about how to treat a child and family. Managed care entities develop these for all conditions covered and usually require all providers in their network to use them.

For lack of either a national child policy or effective state-level interagency planning for children with mental, emotional and behavioral disorders, more and more children are at risk.

As states introduce managed care into this environment, it is critical for them to plan adequately for children's needs. Child mental health services cannot be an afterthought or a footnote to an adult managed mental health care plan. And simply putting a managed care system on top of a non-system for children will not improve or enhance services for children and their families. The problems with the current system create a significant barrier to good services for children and their families. Effective managed care will require responsive funding, good collaborative planning and family involvement.

Effective systems to address these problems have been developed and implemented through a number of demonstration programs and a few state-wide initiatives. Interagency systems of care for children with serious emotional disturbance have been pioneered through the Child and Adolescent Service Systems Program (CASSP) and demonstrated as effective through the Robert Wood Johnson Foundation. Local systems addressing the mental health needs of all children have been developed through a special initiative of the Annie E. Casey Foundation. State-based system reforms have also been initiated, such as the restructure of the child welfare system in Alabama stemming from a lawsuit, currently known as *R.C. v. Nachman*, brought by the Bazelon Center. These demonstrations show that better systems can be developed and that they can be successful.

Families and advocates participating in the development of managed mental health care for children must insist that the problems in the state's current child mental health system be adequately addressed. And as states' new managed care systems are developed and put in place, family and child advocates must be extremely vocal about the special needs of children and the thorny policy issues related to implementation of strong systems of community-based care for children and families.

The recommendations in this publication begin to address these difficult policy questions.

INFORMATION ON MANAGED CARE

Public agencies that fund mental health services are increasingly using new ways to organize and deliver care. As a result, new words are being used to describe how people can get mental health services, use them and pay for them. More and more consumers find themselves dealing with new systems—health maintenance organizations (HMOs), preferred provider networks (PPOs), primary care case managers or point-of-service plans. The overall term for these new approaches is “managed care.”

Child and family advocacy groups should not let the technical terms and aspects of managed care divert them from their goals. Discussion of managed care raises the same policy concerns about children’s mental health that families and advocates have struggled with for years. The goals of a managed care system should be the same as the goals of any good public system.

Child and family advocates will also find new allies among the other organizations working on the issue of managed care, including protection and advocacy systems, advocacy groups for low-income and Medicaid populations, mental health advocates and mental health providers.

Why Is Everyone Talking About Managed Care?

Managed care has been used by private health insurance companies and large corporations for over 20 years. Now state policymakers are turning to managed care in an attempt to organize services better and cut costs in public programs such as Medicaid, mental health and child welfare. Nearly all states are developing or implementing managed care plans for children and adults who need mental health and substance abuse services. Such plans are commonly called managed behavioral health care plans.

Families and advocates can use managed care as a tool for reforming mental health care for children of all ages. In the 1960s, “deinstitutionalization” was the major reform, greatly reducing the use of large state institutions for both adults and children. More recently, community-based systems of care have been developed with the encouragement of the federal Child and Adolescent Service System Program, known as CASSP. These systems emphasize services to support families and help children remain at or close to home and do well in their own community. Such systems of care bring together all the public agencies providing services—the mental health, substance abuse, child welfare, education/special education, juvenile justice and health agencies—to collaborate in meeting the needs of children with mental, emotional and behavioral

disorders and their families. (A description of the CASSP system of care appears in the appendix.)

Properly designed, managed care can be used to develop and shape organized systems of care for children with mental, emotional and behavioral disorders. Under an effective managed care system, each child and family should receive the right services at the right time in the right amount—no more, no less.

What Is Managed Care?

In this guide, the term managed care refers to any system that provides services to an individual child and/or family in return for a fixed fee, requires children and families to use specific providers and periodically reviews the need for treatment, services and supports.

There are different ways to provide behavioral health care in a managed care plan. Some plans are comprehensive and include physical as well as mental health services. Other systems “carve out” mental health services from other health care and provide them through a completely separate managed care plan. Some plans fall between these extremes, providing routine mental health care through the basic plan while covering treatment, services and supports for more severe or long-term mental health problems through either a separate managed care plan or the traditional fee-for-service system.

How Managed Care Plans Operate

Managed care entity—an organization that either directly provides or arranges managed health care.

Capitation rate—a fixed amount paid per person for covered services for a specific time period, usually calculated for each person per month.

A *managed care entity 1* usually receives a set fee for each person it agrees to serve. The fee is paid either by an insurance company or an employer, or by a family or individual. In a publicly funded program (such as Medicaid, mental health or child welfare), it is paid by the state.

In return for this fee, the managed care entity agrees to provide specific mental and/or physical health care services. As a general rule, the managed care entity is paid the same amount, known as a *capitation rate*, for each person, no matter how much the person uses the services.

In the public sector, the extent of coverage under managed care is usually defined in a contract and will partly depend on the fee the managed care entity receives. For example, a Medicaid managed care plan with a high capitation rate is likely to have a broader range of mental health services than a plan with a lower capitation rate, and is likely to allow children and families to use these services more often.

The managed care entity agrees to provide, when necessary, any of the covered services to any participating child and family, even if this results in

costs higher than the capitation rate. Managed care entities, therefore, have incentives to control the use of services very closely.

Sometimes this is done by limiting the kinds of services that physicians and other mental health professionals can offer a family. Managed care plans have their own standards (called guidelines or protocols) to decide the type of benefit and level of care appropriate for each individual. The standards may limit the number of times a child or family can be seen or the length of time they can receive a service or support. To avoid losing money, some plans may not provide the services a family believes a child needs. Sometimes, providers may even fail to speak frankly with families about the level of care needed, or may not make a referral to a specialist because it is against the policy of the managed care entity to do so. In such cases, it is important for families to understand how to appeal on behalf of their child.

In many situations, managed care entities control costs by reviewing decisions about treatment and services. Service providers may have to seek approval for certain services and the managed care entity will consider both its cost and the child's need. This process is called utilization review. Reviewers generally look at the cost, medical necessity and appropriateness of the requested services for a child's condition:

- ☐ Is the service necessary? Are the child's symptoms or behaviors serious enough to justify the current level of care?
- ☐ Is the service appropriate to treat the child's condition? Would a different type of service be more cost-effective?
- ☐ Is there benefit? Does the child show progress or other signs that justify continuing this treatment?

For services to be provided, the reviewer must approve them using the managed care entity's criteria on necessity and appropriateness of treatment.

How Managed Care Works in the Public Sector

Mental health and other state agencies are now seriously planning—and in a few states, actually using—managed care systems. Many individuals who are covered by Medicaid already receive their services through managed care. Increasingly, state officials are talking about combining Medicaid, mental health, substance abuse and sometimes child welfare funds to develop an interagency managed care system for children with mental, emotional or behavioral disorders.

A state that requires individuals who are eligible for Medicaid to join a managed care plan must have approval from the federal government. The federal Health Care Financing Administration (HCFA) allows states to waive

Waiver—Medicaid waivers are granted by the federal Health Care Financing Administration allowing a state to operate its Medicaid program in a way that does not comply with all requirements of federal law.

(that is, not follow) certain Medicaid requirements if it finds the state's managed care plan acceptable. When a state requests such a *Medicaid waiver*, it must solicit and take into account the opinions of concerned citizens, such as families and advocates for children with mental, emotional and behavioral disorders.

In some states, the managed care system may be run entirely through public-sector programs that already exist, such as community mental health centers. Other states are looking to private, for-profit managed care companies to operate managed care systems under a contract with the state. In some states, the decision about managed care may be shifted to the county or to a regional body.

When there is a contract with a private firm, this contract determines: (1) who will be served, (2) what services will be provided, (3) how much the managed care entity will be paid for each adult and child enrolled, (4) the standards for evaluating the services, (5) what reports will be produced, (6) how families can appeal decisions they don't like, and (7) all other aspects of the managed care system. Managed care companies are only required to do what is spelled out in their contract. A company cannot be compelled to do anything that is not in the contract, even if it would clearly be good policy.

Where the public sector operates a managed care system, a public planning document should include the same description of how the system will operate. Later in this guide there is more information about how families can influence the design of the managed care contract or managed care plan.

Regardless of who will run the managed care system, the state as the purchaser of services must ensure that an appropriate community-based system of care is developed. The services that children receive through a managed care entity can and should be consistent with the CASSP system of care as discussed on page 3 and spelled out item 2 of the appendix.

A system of care offers flexible, individualized services using the most appropriate and least restrictive alternatives and making available a full array of services and supports. It relies on *case management* to coordinate care and can lower costs through an appropriate mix of inexpensive or moderately priced family support and other services, without reducing overall responsiveness to the child's needs.

Families, too, want managed care to provide appropriate services for their children through a flexible system that funds the services and supports each child needs. Unfortunately, much of managed care falls far short of this goal by emphasizing cost controls and profit-making over quality care. Poorly run managed care can limit access to care and result in denial of necessary services and supports. Well-run managed care that follows the principles and guidelines in this document and that is adequately funded should control health care costs while maintaining quality.

Case management—case managers, also called service coordinators, help families locate and receive all the services they need, working with all the agencies and providers involved with the child and family.

To create a well-run and cost-effective managed care system, states must begin with a core set of principles, such as the Guiding Principles for Managed Care described in the box on the next page.

STRATEGIES FOR ADVOCACY

Current policy discussions about the use of managed care for publicly financed mental health and family support services are very important to families. Family advocates should see this as an opportunity to press for a restructuring of their state's system to follow both the philosophy of the systems-of-care approach pioneered by CASSP and the Guiding Principles on Managed Care described in the box on page 8. Given the problems with child mental health systems in most states, it is very important for child and family advocates to become involved. The steps in this section point the way.

1. Be at the Table

In every state and community there are ways for child and family advocacy organizations to help shape the managed behavioral health care system. Families and family organizations have been and must continue to be significantly engaged in policymaking at the state and local levels. They should not underestimate either their collective voice or their individual power as customers. They know what services and supports help their children, so they can convincingly suggest how public officials can design the most effective and cost-efficient managed care plan for children.

From the beginning, the planning, development, implementation and monitoring of public managed care systems should be informed by families and other advocates for children. And managed care entities running public-sector programs should involve families and family organizations on advisory boards and in other aspects of the operation of their plan.

To be effective, families and advocates should both gather information and polish their communication and negotiation skills. They will also want to strengthen partnerships with others who seek to improve the quality of life for children with mental health needs. The following strategies provide a general guide for influencing public-sector managed care as it emerges. Each group will want to tailor its activities to its own state or community.

Guiding Principles on Managed Care for Children with Mental, Emotional and Behavioral Disorders

- ☐ Families should be involved as full participants in all aspects of the planning, delivery and evaluation of managed behavioral health care services and supports for children and youth.
- ☐ Managed behavioral health care systems should protect the rights of children, youth and families and promote advocacy on their behalf.
- ☐ Managed behavioral health care should individualize services in accordance with the unique strengths and needs of children and youth with mental, emotional or behavioral problems and their families.
- ☐ Managed behavioral health care should be sensitive and responsive to racial, ethnic, linguistic and cultural differences.
- ☐ Managed behavioral health care should recognize that children are not little adults and that there must be separate planning for children and youth which addresses their physical, emotional, social and educational needs in a comprehensive and coordinated fashion, in the context of their family, school and community.
- ☐ Managed behavioral health care should promote early identification of problems, ensure early intervention and encourage activities that identify and improve or remedy environmental factors that put children at risk for developing mental, emotional or behavioral problems.
- ☐ Managed behavioral health care should provide services for children and youth that support their participation in the least restrictive, most normal environment appropriate for their health and safety, preferably within their homes and communities.
- ☐ Managed behavioral health care should integrate services and supports for children and families by using (or creating) linkages among the agencies with responsibility for children and youth.
- ☐ Managed behavioral health care should utilize service coordinators (sometimes called case managers) to ensure that multiple services are delivered in a coordinated and effective manner in accordance with each child's and family's changing needs.
- ☐ Managed behavioral health care should ensure that children and youth experience smooth transitions, such as when returning from residential placements to their community or from youth services into the adult system, if that is necessary.
- ☐ Managed behavioral health care systems must have sufficient resources to provide high-quality care

- ☐ **Gather information** about both the potential of managed behavioral health care for children and youth and about the pitfalls. Become familiar with the "language of managed care," its vocabulary and definitions. Learn about the system's structure, regulations and providers.
- ☐ **Seek out key individuals** who are making or could influence decisions about managed care for children and youth in the state. These people may be in any or all of the following agencies:
 - Medicaid agency
 - child welfare agency
 - mental health agency
 - health agency
 - office of the secretary of the department of human services
 - Governor's office (chief of staff, legislative coordinator, children's liaison)
 - Office of Children (if the state has one)
 - legislative committees and staff
- ☐ **Find out which state agency's resources will pay the most** toward the cost of the managed care system; this will identify who is really in charge.
- ☐ **Identify key individuals** who will listen to the views of families and advocates. Always try to reach officials in the Medicaid agency if a Medicaid waiver is planned. However, do not ignore traditionally supportive offices in the state legislature or in state agencies, especially child mental health specialists in the mental health or child welfare agencies.
- ☐ **Educate these critical decisionmakers** to help them understand family perspectives, concerns and experiences so these can be incorporated into the managed care design.
- ☐ **Be persistent.** Expect a lengthy process with stops and starts, successes and setbacks. Stick with it to the end to make a real difference in the lives of children and families.
- ☐ **Communicate effectively** with the public and policymakers. Learn strategies for negotiation and diplomacy to speak effectively with or write to government officials, policymakers and managed care administrators.
- ☐ **Reach out to professionals** in the community, such as physicians, teachers, early childhood programs (like Head Start, day care providers, etc.), juvenile justice personnel, family court judges and others who come in contact with children and their families. Enlist their support and involvement in ensuring an effective managed care system.

- ☐ **Build partnerships** with providers and other advocates in the community who share concern for improving the mental health of children and youth. Consider working with protection and advocacy systems, health care advocates and others. Work with them to share decisionmaking, promote family leadership and expand the base of support for the system of care.
- ☐ **Educate the public** to win support for quality managed care. Use the local media, community meetings, churches and social clubs to enlist allies and increase understanding of both the possibilities and the pitfalls.
- ☐ **Find resources** to help fund family information networks, disseminate information, train families and support family participation in key activities of the managed care entity.

Family and other organizations advocating for good managed behavioral health care for children and youth need to take advantage of every opportunity to get their message across. While the procedures for planning and setting up a managed care system will vary from state to state, the following list includes the most common activities in which groups should become involved:

- planning groups or task forces set up by state agencies;
- private meetings with key state decisionmakers (see list on page 9);
- public meetings set up by state officials;
- state legislative hearings;
- public hearings on the managed care plan's impact on Medicaid (states are required to solicit public input—usually done through public hearings—when developing a federal Medicaid waiver allowing them to include Medicaid beneficiaries in mandatory managed care plans);
- Request for Information (RFI), a procedure for states to get information from managed care companies on various aspects of managed behavioral health care, such as benefit packages, appropriate rates to pay for covered services, etc. (families should be sure their concerns are reflected in the RFI and that the information obtained is made public);
- Request for Proposals (RFP), the process by which the state asks managed care companies to submit bids (more on RFPs below);
- review of bids submitted by managed care companies in response to an RFP; and
- writing of the contract between the state and the managed care company that has won the contract.

All of these are opportunities for involvement. Family organizations should nominate their members and allies to serve on planning boards and advisory councils. Family and child advocacy organizations should request their own meetings with key officials. Further, they should always be present

and very visible at public hearings on the managed care plan and at legislative hearings, even when not invited or allowed to participate formally.

One of the most important steps of all is the development of the Request for Proposals (RFP). Child and family advocacy organizations must work to influence the RFP process because the contract with the managed care company will be written from the RFP. If a critical issue is not addressed in the RFP, it is not likely to be in the contract. Family and advocacy organizations should be sure their major concerns are understood before the RFP is even drafted.

Often family organizations and other advocates can provide written comments on the RFP and speak at a public hearing. More effective, however, is to meet with someone in the agency issuing the RFP. The agency may have an individual who coordinates with advocacy groups. Getting to know this person (or group of persons) is extremely important.

2. Use Materials Wisely

In the early stages, when state officials are developing their outline of how managed care will operate in the state, it is important for family organizations and other child advocates to emphasize the fundamental principles for good managed care for children and youth. Distribute copies of the Guiding Principles (page 8) at every opportunity. If any state officials are unfamiliar with the CASSP system of care, give them the handout on systems-of-care (item 2 in the appendix).

As the discussions get more specific, you will want detailed recommendations to back up the Guiding Principles. At this stage, the Federation's Principles of Family Involvement in the Development and Operation of Managed Care Systems (in the appendix) should be widely circulated to explain the role families should play in development and operation of managed care.

One of the early decisions that should be made is for the managed care plan to have a clear focus on the needs of children and youth. To help convince policymakers of the need for such a focus, use the handout in the appendix, *Why Children Are Not Little Adults*. Some states address the need effectively by having a completely separate plan for children's services.

As discussions continue, family and child advocacy groups will want to raise the right questions about various aspects of the managed care system. The next section presents questions on critical issues that will highlight for policymakers how best to meet the needs of children and families.

3. Raise Critical Issues

The following questions highlight elements of good managed care that are critical to children with mental, emotional and behavioral disorders and their families. All of these should be addressed in the plan for managed care, detailed in the RFP and, ultimately, answered by the contract.

Will the managed behavioral health care entity provide services and supports specifically designed for children and youth as well as services for adults?

All family- and child-serving systems, including managed care, must be able to respond rapidly and appropriately to the changing physical, emotional, mental and social development of infants, toddlers, children and youth. Ask the following questions:

- ☐ Is the state plan for behavioral health care for children separate from the adult plan?
- ☐ Does the plan require the managed care entity to assess the changing physical, mental and emotional development of children frequently?
- ☐ Does the plan recognize the importance of the family's role with respect to children's health?
- ☐ Does the plan emphasize screening, prevention and early intervention for children of all ages?
- ☐ Does the plan reflect the need to recognize the developmental stages and transition points that are critical for children and families?

Will the managed behavioral health care entity operate in a family-friendly manner?

Too often mental health and other public systems are set up for the convenience of providers. For services for children to be effective, however, they must be offered in a family-friendly manner. With its emphasis on consumer satisfaction, managed care should be able to provide services in a way that is acceptable to all families. Ask the following questions:

- ☐ Will children and families always have to go to the provider's office?
- ☐ Can providers come to families' homes in the evening, go to schools or meet with youth at other places in the community?
- ☐ Will the managed care entity provide services at times that are convenient for children and families?

Co-payment—a set amount that an individual pays for health care services in addition to the amount paid by the private insurer or state agency, such as Medicaid.

- ☐ Will the managed care entity have a consumer oversight board to review implementation of the plan? Will this board include families with children who have mental, emotional or behavioral problems?
- ☐ Will the managed care entity give families educational materials about the plan, including what services are available, who is eligible for them and how to get them?
- ☐ Will services be accessible by public transportation? Will individuals who need help getting transportation to services receive it?
- ☐ Does the plan have *co-payments*? If so, are they low enough so as not to be a serious barrier to getting care?

will families be fully involved in their child's care?

Serving children means sharing responsibility for care with a family and involving them in developing and evaluating the plan of services, supports and treatments. Any decision about services for children must be made with active family participation. Ask the following questions:

- ☐ Will the managed care entity provide services and supports to sustain the family as a strong and viable unit? Does it help ensure that primary care givers have the skills and resources they need to raise children at home?
- ☐ Will the managed care entity conduct screening and assessment activities that explore the strengths and needs of children and families?
- ☐ Will children and families be fully involved in the development and evaluation of the plan of care?
- ☐ Will the managed care entity include the family in all phases of the design and implementation of services and supports, even when placement is away from home?
- ☐ Will the state monitor the managed care plan's receptivity to family involvement in their child's care, using written assessment measures developed specifically to test whether a system is responsive to family needs?²

Does the managed care plan emphasize the need for prevention, early detection and early intervention?

A good managed care system should focus on prevention, early detection and early intervention using home- and community-based services and supports as much as possible. By making early treatment a priority, managed care entities can reduce excessive costs and avoid out-of-home placements and families can receive the services their children need in a timely fashion. Ask the following questions:

- ☐ Does the managed care plan include developmental, psychological and social functioning assessments in all well-child checkups?
- ☐ Does the managed care plan require pediatricians to be trained to recognize developing mental health problems in children?
- ☐ Does the managed care plan monitor the development of children and youth who are likely to be at risk of developing a mental, emotional or behavioral disorder (such as children who are living with a primary care giver who has a problem with substance abuse or a mental illness)?
- ☐ Does the managed care plan encourage providers to work with children and their families at their homes and in other natural settings?
- ☐ Does the managed care plan provide education to parents concerning their child's disorder and training in how they can improve the child's behavior at home, in school and in the community?

will the managed behavioral health care entity provide home- and community-based services and supports as part of a comprehensive array of services?

Too often mental health services are limited to medication management, individual and group therapy, day treatment and psychiatric hospitalization. Moving the point of service delivery to natural environments—such as the family, school or recreation center—helps ensure that the service will relate to the child's life. Also children and families served in natural, familiar or comfortable settings will be more likely to be engaged and to use their new insights and skills in facing daily challenges. Ask the following questions:

- ☐ Will the managed care entity provide care on an individualized basis, using a wraparound approach to meeting specific needs of a child and family?
- ☐ Will the managed care entity pay for family supports such as respite care and family-support groups?
- ☐ Do covered services include specialized programs needed by very young children, such as nutrition, language and communication development, and play groups?
- ☐ Will the managed care entity provide an interdisciplinary team and a service coordinator who can help families arrange all the services and supports the child and family receive from different agencies?
- ☐ Has the state ensured that all relevant agencies will work as a team with the managed care entity, jointly planning services and pooling resources to provide a full array of services?

- ☐ Will the managed care entity participate in collaborative interagency planning to ensure children and families are served efficiently and effectively?

Does the plan adapt to the different cultures of the families it serves?

Managed care entities should acknowledge and respect the cultural values and languages of the families and children they serve and should be responsive to the ways various cultural groups seek help. "Customer satisfaction" may be different for various cultural groups. Services and supports should be provided in ways that are compatible with the attitudes and beliefs that different cultures associate with illness and treatment. Ask the following questions:

- ☐ Are services and supports offered by individuals who understand and respect the family's culture?
- ☐ Does the managed care entity use providers who speak the languages of the families enrolled?
- ☐ Will the managed care entity pay for services from culturally grounded, non-traditional providers and for natural supports, such as kinship care, *curanderos*, medicine men or other trained healers?
- ☐ Does the managed care entity hire members of the community to help inform and learn from families about their children?
- ☐ Does the managed care entity provide services in locations that are easy for families to get to and where they feel comfortable going for help?
- ☐ Are the managed care plan's materials produced in all languages commonly used in the community and on audio tape and in Braille?

Will the managed behavioral health care entity recognize families and children as their principle customers and evaluate "customer satisfaction" in a way that shows positive results for children and families?

Managed behavioral health care entities are typically interested in customer satisfaction because, for obvious financial reasons, they do not want to lose enrollees or lose their contract with the state. However, "customer satisfaction" can have different meanings to families, to those who provide mental health care and to those who pay for it. Ask the following questions:

- ☐ Will the managed care entity regularly conduct consumer satisfaction surveys, focus groups and other activities to learn the opinions of families and youth?

- ☐ Will the plan invite truthful responses from families and youth by using families or family groups to ask the questions so that families are not afraid to criticize the plan or the services they receive?
- ☐ Will the managed care entity use survey results to improve the way it delivers services to children and families?
- ☐ Will the managed care entity use the results to get better outcomes for children and their families?

Does the plan provide adequate grievance procedures?

Families should be able, without the risk that their child will lose benefits, to appeal the denial of services and to refuse any services, supports or treatments for their child that they do not feel are appropriate.

Every managed care plan should ensure easy access to a grievance procedure for families to appeal any decision about their child. Ask the following questions:

- ☐ Do families have the right to file a complaint at any time?
- ☐ Are families given information explaining clearly when the grievance procedure can be used and how to start the process?
- ☐ Does the managed care plan guarantee that families will receive a prompt response (within 15 days) to any complaint or grievance?
- ☐ Is a quick-response system available for use to settle a grievance within 24 hours when the child's health or safety is at risk?
- ☐ Can families file a grievance about all of the following?
 - delay or denial of service;
 - poor quality of care;
 - pressure to accept treatment that they do not choose or that they believe is inappropriate;
 - lack of access to necessary specialty services;
 - refusal by a *primary care* provider to authorize specialist services; or
 - cultural insensitivity that limits their ability to obtain care.
- ☐ Does a consumer oversight board review complaints and the results of grievance proceedings?

Primary health care—
professional and related
services administered by
an internist, family
practitioner or
pediatrician on an
outpatient basis.

Will the plan have consumer protections?

Some managed care plans have been criticized for their failure to protect consumers and ensure appropriate services. Managed care plans should be required to employ basic consumer protections. Ask the following questions:

- ☐ Are there adequate assurances that children and families will have access to providers?
- ☐ Does the managed care company have good treatment protocols and will it make them available to the individuals enrolled and to the public?
- ☐ Are utilization review practices regulated to focus primarily on areas of greatest cost and to avoid hassling families seeking early intervention and low-cost options?
- ☐ Will families be given information regarding any utilization review practices used and review decisions made about services for their child and the family?
- ☐ Will the state regulate managed care entities? For example, will inappropriate marketing practices be prohibited?

Does the managed behavioral health care plan have sufficient financial resources?

It is very important that public agencies make sure that a managed behavioral health care company has enough money to do the job right. Public agencies should also limit the managed care entity's profits and reinvest any extra savings to promote earlier identification of mental health problems and expand community-based services and family supports. Ask the following questions:

- ☐ What are the various sources of funds that will pay for managed behavioral health care for children and youth? Will the plan have adequate financial resources from these sources?
- ☐ Is the capitation rate reasonable?³
- ☐ Will all public child-serving systems—the child welfare, education and special education, juvenile justice, substance abuse, health and mental health agencies—pool financing and services to create a single, coordinated system of managed care for children?

Will families be offered help in negotiating the managed care system if they need it? Are family groups funded for these purposes? Are advocacy and ombudsperson programs available?

Individual families should have somewhere to turn for help in understanding and advocating for their child's rights. In addition, the state should support family organizations and other entities to track the activities of the managed care plan and provide feedback to the state on issues that families face. In planning managed care, the state must address the need for individual case

Ombudsperson—a person who can help a family obtain information, explain it to them, investigate complaints and resolve disagreements with a managed care entity.

advocacy, *ombudsperson* and evaluation activities. Ask the following questions:

- ☐ Does the managed care entity provide resources for family organizations to help individual families use the grievance procedures?
- ☐ Will the managed care entity, or the state, allocate resources to support family networks that gather and distribute information about the plan's use and its services, train family members in evaluation and give feedback to the managed care administrators?⁴
- ☐ Has the state set up one or more organizations to provide individual advocacy for families, such as a new ombudsperson program, or arranged for an existing advocacy organization, such as a family organization or the state's protection and advocacy system, to do this?

Will the managed care plan emphasize the outcome of services and supports on children's lives? Will it deliver quality services and set priorities that will help children succeed?

Families and advocates for children's mental health need to be clear about what they expect from managed behavioral health care—in other words, what *outcomes* they want from the system. Whatever the nature of the managed behavioral health care entity, there will be some kind of report about outcomes—even if it only says that managed care costs less. However, families will only view managed behavioral health care as a “success” if they can see that their children benefit. Families and their advocates should work with the public agencies that purchase or provide managed care to identify good measures of family satisfaction and positive outcomes for children. Ask the following questions:

- ☐ Will managed care provide supports that make it possible for children and youth to achieve a level of independence appropriate to their age and development?
- ☐ Will the managed care plan keep data on the success of children and youth as measured by attending school, staying in class, completing assignments, improving grades and eventually graduating?
- ☐ Will managed care provide the supports that make it possible for children and youth to live at home and to function within their family, school and community?
- ☐ Will managed care address the need for youth to make a successful transition to adult mental health services, when that is necessary?

- ☐ Will the managed care plan be judged (and rewarded) based on improved outcomes for children in its care, measured by such factors as:
- higher levels of social functioning;
 - improved physical health;
 - improved school performance;
 - reduction in symptoms;
 - optimal family autonomy and ability to act as a unit;
 - more children living at home and in the community;
 - fewer residential placements;
 - fewer interactions with the juvenile justice system?

Does the state's plan for managed care emphasize quality as much as it does cost savings?

Managed care has often been criticized for its focus on cutting costs. However, the financial goals of managed care can be entirely compatible with the goals of a public system of care for children with mental, emotional and behavioral disorder that is based on the CASSP principles.⁵ This will only occur, however, if the managed care plan is carefully designed to support families, to emphasize quality care and to make care readily accessible when needed. Money should be saved by being more efficient and effective, not by denying necessary services. Ask the following questions:

- ☐ Has the state provided incentives that will reward good quality and appropriate care?
- ☐ Will the state regulate profits of private for-profit companies?
- ☐ Will savings realized by managed care be reinvested in programs and services needed by children and their families?

CHALLENGES OF MANAGED CARE

We offer this guide to family and child advocacy groups to explain the basics of managed care and inform their decision-making in a managed care environment. Managed care offers families with children who have mental, emotional or behavioral problems both challenges and opportunities.

Managed care is frequently criticized because policy-makers have emphasized short-term cost savings at the expense of long-term outcomes and savings

that result from a quality system. Too often, the state emphasizes only the savings it can achieve. The companies receiving managed care contracts from states are also criticized for being inexperienced in managing care for children and youth with serious emotional disorders and for being unfamiliar with the broad array of services and supports that are needed to help children succeed.

Children and families are best served by quality systems that offer comprehensive home- and community-based care. Yet such systems are now available only in a few jurisdictions or through isolated demonstration programs. Family organizations and advocates for children with mental health needs should participate meaningfully in designing a managed care plan that will emphasize quality as much as cost and actually improve the child mental health system in their state. They should educate legislators, child-serving agency administrators and managed care entities about services and supports that respect families and return good value for the public dollar. Follow the advice in this guide, use your own experience of what works and rely on your knowledge of the strengths and weaknesses of your own state system.

While this guide is copyrighted and the main body of the text may not be copied without permission, we have designed some pages as handouts for training and use in meetings with policymakers and managed care company executives. You are encouraged to copy and distribute the Guiding Principles for Managed Care on page 8 and the handouts in the appendix.

FOR MORE INFORMATION

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NOTES

1. In this guide, the term managed care entity is used to refer to the party running the managed care program, whether that is a private company, a nonprofit provider, a state agency or a county or other public authority.
2. These measures are: the Family-Centered Behavior Scale developed by the Beach Center on Families and Disability, University of Kansas, Lawrence, Kansas; the Client Satisfaction Questionnaire (CSQ), the Youth Satisfaction Questionnaire (YSQ), the Family Empowerment Scale (FES) and the Family/Professional Collaboration Scale, all developed by Portland State University, Regional Research Institute for Human Services, Oregon Partners Project Evaluation, Portland State University, PO Box 751, Portland, Oregon 97207. Also: the Vanderbilt Institute Center for Mental Health Policy has developed a comprehensive array of satisfaction measures which can be obtained from the Resource Specialist, Center for Mental Health Policy, Vanderbilt Institute for Public Policy, Box 163, Nashville, TN 37203.
3. For further information on this issue, see *Managing Managed Care*, available from the Bazelon Center for Mental Health Law and described in the section on Additional Reading on page 25.
4. Family organizations in some states (e.g., Arizona and Vermont) are already doing this. For further information, contact the Federation of Families for Children's Mental Health.
5. See Lourie, I., Howe, S. & Roebuck, L. (April 1996). *Systematic Approaches to Mental Health Care in the Private Sector for Children, Adolescents and Their Families: Managed Care Organizations and Service Providers*. Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

GLOSSARY

Managed care has its own jargon, but many of the concepts are straightforward. Often they are not new concepts, just new words for familiar concerns. The following list should be helpful in understanding conversations about managed care.

Capitation rate—a fixed amount of money paid per person for covered services for a specific time period, usually calculated for each person per month.

Carve-out—a way to provide and finance specific health care services (e.g., mental health) separately from general health care services.

Case management—see service coordinator.

Co-payment—a set amount of money that an individual pays for health care services in addition to the amount paid by the private insurer or state agency (e.g., Medicaid).

Fee for service—paying a specific amount for a specific service, such as an office visit or medication check.

Gatekeeper—primary care physician responsible for coordinating and managing the health care needs of members. Generally, in order for specialty services, such as mental health and hospital care, to be covered, the gatekeeper must first provide or approve the referral.

Health maintenance organization (HMO)—an organized system of health care that provides directly or arranges a comprehensive range of basic and supplemental health care services for individuals who are enrolled to receive these services; the arrangement is primarily for each member to receive prepaid services on a fixed periodic basis.

Managed care entity—an organization that either directly provides or arranges managed health care.

Managed care organization (MCO)—an organization that provides or arranges managed health care; see managed care entity.

Managed behavioral health care—managed mental health and substance abuse benefits.

Medically necessary—a decision made by the managed care entity to determine if requested medical interventions or services are necessary for a particular individual.

Ombudsperson—a person who can help a family obtain information, explain it to them and investigate complaints and resolve disagreements with a managed care company.

Outcomes—an assessment of the impact of health services in terms of improved quality of life and/or daily functioning.

Out-of-network—services provided to patients by providers who are not part of the managed care plan's network (not on its list of approved providers).

Point-of-service plan—a modified managed care plan where members do not have to choose how to receive services until they need them. Members receive coverage at a reduced level if they use a non-network provider.

Pre-admission review and **prior authorization**—the approval a provider must have from the managed care entity before providing certain services, particularly inpatient hospital care.

Preferred provider organization (PPO)—a network of providers that agree to accept negotiated fees in return for prompt payment and a certain volume of patients. Individuals enrolled in a PPO network can use non-network providers at their own additional expense.

Primary care—professional and related services administered by an internist, family practitioner or pediatrician on an outpatient basis.

Provider networks—group of organizations or individuals that agree to provide and are reimbursed for health care services to members of a managed care plan.

Quality assurance—systematic efforts to review and improve the quality of services by using a set of measures, requirements and tasks, such as grievance procedures, utilization review and treatment guidelines.

Quality improvement—sometimes called continuous quality improvement, a management principle that emphasizes ongoing improvement in service delivery through a system of internal monitoring and feedback so that improvements in quality of care can be made.

Quality management—the process by which a managed care entity measures the extent to which its providers conform to defined standards, and uses that data to improve care and outcomes.

Report card—a published report for consumers on the premium costs for a plan and overall quality of a health plan or provider. Report cards generally include measures of the plan's delivery of appropriate services, patient outcomes, patient satisfaction and cost structure (see outcomes).

Requests for proposals (RFPs)—the process followed when companies or agencies want a specific job completed, such as delivery of mental health services, usually for a set amount of money. People submit bids explaining how they would provide the requested services and how much it would cost.

Risk—the possibility that revenues of the insurer will not be sufficient to cover expenditures incurred in the delivery of contractual services. A managed care provider is at risk if actual expenses exceed the payment amount.

Risk sharing—when the managed care entity assumes responsibility for services for a specific group but is protected against unexpectedly high costs by a prearranged agreement for higher payment for individuals who need significantly more costly services. Risk is usually shared by the managed care entity and the state.

Service coordinator—an individual who helps a family locate and receive all the services they need. Responsibilities include working with all the agencies and providers involved with the child and family.

System of care—coordinated, collaborative networks of child-caring agencies that provide a broad range of flexible, individualized, community-based services selected with family consultation.

Treatment protocols—a pre-set pattern to guide clinical decisions about how to treat a child and family. Managed care entities develop these for all the different conditions covered and distribute them to providers in their network, who are usually required to follow them.

Treatment reviewers—managed care staff members who decide what type of care and services an enrollee can receive and for how long the services will be provided.

Utilization review—a mechanism used by some insurers and employers to evaluate use of and requests for health care on the basis of necessity, appropriateness and quality.

Waiver—a Medicaid term. Medicaid waivers are granted by the federal Health Care Financing Administration (HCFA) to allow a state to operate its Medicaid program in a way that does not comply with all requirements of federal law. There are two types of Medicaid waivers for managed care:

- Section 1915(b), a more narrow waiver that leaves in place certain federal requirements, such as how many non-Medicaid individuals must be in any health maintenance organization used by Medicaid in the state. A 1915(b) waiver permits the state to require individuals to enroll in managed care programs or to select a physician to serve as their primary care case manager. 1915(b) is often used when a state applies for a behavioral health care managed care plan separate from physical health care.
- Section 1115, a very broad waiver that allows states to add individuals to their Medicaid program and to operate managed care on a broad scale with few federal rules. Usually used when states are addressing health care reform issues.

ADDITIONAL READING

On Issues Relating to Managed Care for Children and Youth:

- Koyanagi, C. (1995). *Managing Managed Care for Publicly Financed Mental Health Services*. Washington, DC: Bazelon Center for Mental Health Law.
- Koyanagi, C. (1996). *Managed Mental Health Care: Survey of the States*. Washington, DC: Bazelon Center for Mental Health Law.
- Pires, S. A., Stroul, B. A., Roebuck, L., Friedman, R. M., McDonald, B. B. & Chambers, K. L. (1996). *Health Care Reform Tracking Project: Tracking State Health Care Reforms as They Affect Children and Adolescents with Emotional Disorders and Their Families*. Tampa, FL: Research. State Mental Health Representative for Children and Youth. (1995). *Successful Integration of System of Care Development with Managed Behavioral Healthcare Technologies in Public Children's Mental Health: Work in Progress*. Alexandria, VA: National Association of State Mental Health Program Directors.
- Stroul, B. A. (1996). *Managed Care and Children's Mental Health: Summary of the May 1995 State Managed Care Meeting*, Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

On Systems of Care:

- Lourie, I., Howe, S. & Roebuck, L. (1996). *Systematic Approaches to Mental Health Care in the Private Sector for Children, Adolescents and Their Families: Managed Care Organizations and Service Providers*. Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.
- Burnim, I., Jackson, S., Schoen, D., Turner, O., Johnson, E. & Cohen, R. (1991). *The R.C. Case: Creating a New System of Care for Children in the Child Protection and Foster Care Systems*. Washington DC: Mental Health Law Project/ Bazelon Center for Mental Health Law.
- Stroul, B. & Friedman, R. (1986). *A System of Care for Severely Emotionally Disturbed Children & Youth*. Washington DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.

On Cultural Competence:

- Cross, T.L., Bazron, B., Dennis, K. & Issacs, M. (1989). *Towards a Culturally Competent System of Care*. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.

On Evaluation of Family Involvement:

- Flint, S. (1995). Model of family involvement in evaluation: Vermont respite program. In *TA Brief*. Boston, MA: The Judge Baker Children's Center (Vol.1, No.1).
- McDonald, E. & Cross, R. (1995). Family outcome measurement in the evaluation of children's mental health services. In *TA Brief*. Boston, MA: The Judge Baker Children's Center (Vol.1, No.1).

On Medicaid Coverage of children's Services:

- Koyanagi, C. & Brodie, J. (1994). *Making Medicaid Work to Fund Intensive Community Services for Children with Serious Emotional Disturbance*. Washington DC: Bazelon Center for Mental Health Law.

APPENDIX

HANDOUTS YOU MAY COPY AND USE

1. Why Children Are Not Little Adults

Use to explain to policymakers and managed care entities why special attention needs to be given to designing the system to meet the specific needs of children and youth, as well as those of adults.

2. The Child & Adolescent Service System Program (CASSP) Principles of Care

Use to educate state officials about the philosophy of the system of care for children with serious emotional disturbance as developed through the federal-state partnership of the Child and Adolescent Service System Program (CASSP).

3. Federation of Families for Children's Mental Health: Principles of Family Involvement in the Development and Operation of Managed Health and Mental Health Care Systems for Children and Youth

Use to explain to policymakers and managed care entities the critical role that families can play to ensure that the system is effective and meaningful, and thus ultimately successful in meeting the needs of youngsters.

4. Principles for Managed Care for Children with Mental, Emotional and Behavioral Disorders

Appears on page 8 of the text. Use in all meetings and public hearings on the managed care plan to explain the fundamental principles of good managed care for children and youth with mental, emotional or behavioral disorders and their families.

WHY CHILDREN ARE NOT LITTLE ADULTS

Making Managed Behavioral Health Care Appropriate for Children and Youth

Children, as a natural result of the process of growing up, are in a constant state of change. Every child is just a little bit different every day. Very young children grow rapidly and noticeably. Change in school-age children is less obvious, but there are big differences over the course of a year. At adolescence, some of the changes—both physical and emotional—are dramatic. Families constantly and automatically adjust their parenting and life style to suit the evolving abilities and needs of their children. It is this dynamic quality that makes children so very different from adults and creates their extended need for adult support and guidance.

Family- and child-serving systems, including managed care, must have the flexibility to respond rapidly and appropriately to the changing physical, emotional, mental and social development of infants, toddlers, children and youth. Quality child- and family-serving systems, including managed care systems should:

- ☐ Assess the child's situation and progress systematically and frequently and use what they learn to improve services and supports.
- ☐ Emphasize screening, prevention and early intervention.
- ☐ Recognize the developmental stages and transition points that are critical for the child.
- ☐ Understand and respond quickly to developmental changes in the child and family.
- ☐ Be flexible so as to respond to the changing and intermittent care needs of a child.

All children, including those with mental, emotional or behavioral problems, continuously require the support of their parents, siblings and other family members. The family, broadly defined, is the most constant element in a child's life. Its culture and values provide the context in which the child develops and influence the way the child thinks, feels, acts and responds to the world. Psychological ties to a family are maintained even when children leave home or the physical bonds no longer exist.

What families know about their children is more comprehensive than information gathered by an evaluation team at a specific point in time. Families have a longitudinal perspective on their child's development, behavioral patterns, characteristic responses to various situations, preferences and idiosyncracies and reactions to previous treatments.

Child- and family-serving systems, including managed care, need to learn and respect what families know, think, feel and believe about their children and the services and supports they are receiving. Serving a child means sharing responsibility for the child's care with a family. Services and supports, such as respite care, that enhance the quality of family life are necessary and legitimate uses of resources designated to serve a child. Quality child- and family-serving systems, including managed care systems, should:

- ☐ Respect the family's culture and values and organize services and supports accordingly.
- ☐ Include the child's family in all phases of assessment and the design and implementation of services and supports, even when the child is placed away from home.
- ☐ Provide services and supports to sustain the family as a strong and viable unit that includes the child and to ensure that primary caregivers have the skills and resources they need to nurture the child.

A child's physical and mental health are intertwined and, together, influence the child's development. Children's need for food, shelter, clothing, education and protection can bring them into contact with a variety of systems, each with its own set of agencies, programs and services. The education and physical health care systems are commonly experienced by all children. However, usually through no fault of their own, some children and youth will also encounter the child welfare, mental health, and substance abuse prevention and treatment systems. And, sadly, when these other systems fail, some children and youth find themselves in the juvenile justice system.

Just as children grow in one piece, so must the child- and family-serving systems, including managed care, meet their needs in one coordinated, efficient and cost-effective effort. Quality child- and family-serving systems, including managed care systems, should:

- ☐ Recognize that the involvement of more than one system will require more time and cost more money, and make plans accordingly. This is especially critical for children who are in state custody or under the jurisdiction of juvenile justice.
- ☐ Provide the child's family with the support of an individual responsible for ensuring close coordination across systems and communication and consistency among the different agencies and programs working with the child and family.
- ☐ Conduct screening and assessment activities that explore the child's and family's strengths and needs across a wide range of domains, with follow-up that gets all the necessary systems involved quickly.
- ☐ Actively engage in collaborative interagency planning to ensure that the child and family are served efficiently and effectively.

SYSTEM OF CARE FOR CHILD AND ADOLESCENT SERVICES

Developed by the Child and Adolescent Service System Program (CASSP)

CORE VALUES

1. The system of care should be child-centered and family-focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community-based, with the locus of services as well as management and decision-making responsibility resting at the community level.
3. The system of care should be culturally competent, with agencies, programs and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

GUIDING PRINCIPLES

1. Children with emotional disturbances should have access to a comprehensive array of services that address the child's physical, emotional, social and educational needs.
2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potential of each child and guided by an individualized service plan.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing and coordinating services.
6. Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that the children can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.

8. Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.
9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and youth with emotional disturbances should be promoted.
10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

Principles of Family Involvement in the Development and Operation of Managed Health and Mental Health Care Systems for Children and Youth, Adopted July 1995

These principles were developed through an interactive process that involved families from a wide diversity of communities representing the spectrum of families raising children with mental health needs, emotional or behavioral problems or mental disorders. These principles represent a consensus. In adopting these principles, the Federation understands that in individual communities there may be additional concerns and that the realization of these principles will necessarily be adapted to local conditions.

I POLICY ISSUES

- 1.1 Family members must be part of the decision making team responsible for managed-care system development. This applies to both the public and private sectors.
 - 1.1.1 The base of parent advocacy needs to be broadened to ensure both depth and diversity of perspectives in planning, policy development, implementation and evaluation of managed care systems. Families reflecting the full economic, cultural, linguistic and racial diversity *who are or will be receiving managed care services* must be included in development of the systems.
 - 1.1.2 State agencies must be aggressive in insuring managed care systems involve families in an ongoing way.
 - 1.1.3 Systems must develop services for the benefit of children and families.
 - 1.1.4 The managed care system must include health care professionals who have specialized knowledge and skills to treat the many faces of children with mental health needs.
 - 1.1.5 Family members must have appropriate representation on advisory boards and other groups that have the power to influence the managed care system.
 - 1.1.6 Concepts and principles of family involvement need be institutionalized throughout the managed care system.
- 1.2 Managed care systems must be consistent with the principles of the system of care. This includes:
 - 1.2.1 Preserving the benefits of interagency collaboration;
 - 1.2.2 Involvement of family members in decision making about the design, delivery and evaluation of services;
 - 1.2.3 Supporting a full continuum of care; and
 - 1.2.4 Providing individualized services tailored to the specific needs of each child and family (including holistic and alternative health care needs justified by medical necessity or personal religious beliefs).

- 1.3 Families need to be involved in the evaluation and assessment of the success of managed care systems.
 - 1.3.1 We must be sure that presenting problems are evaluated and stabilized so that our children can benefit from behavioral health care.
 - 1.3.2 Family members must be members of quality management teams and included in the process of determining outcome measures and data collection systems.
 - 1.3.3 Family members must be included in establishing "best practices" based on their experiences with the system of care.
- 1.4 Family representatives need to be included on the planning teams for all conferences, training and technical assistance concerning managed care.

2 SERVICES-RELATED CONCERNS

- 2.1 Families must receive the information and training to be empowered to advocate for themselves. This includes:
 - 2.1.1 Information about managed care principles, practices and systems design;
 - 2.1.2 Strategies for family involvement; and
 - 2.1.3 Education in the importance of and opportunities for influencing systems change.
 - 2.1.4 Efforts must be made to provide effective outreach to youth and their families in inner city and rural communities in order for them to have equal opportunity to access information and training.
- 2.2 Families must have a definitive role in the development of their child's care plan and service needs.
 - 2.2.1 The "gatekeeping" function of the managed care system must take into consideration and not compromise the role of the family as decision maker for the child. For example, how utilization review of hospitalizations or outpatient treatment is handled affects the family's capacity to protect their child's best interest.
 - 2.2.2 The managed care system must have flexible time frames for services. "One size fits all" does not work.
- 2.3 The providers in the managed care system must be prepared to allow families to participate at whatever level they feel comfortable.
 - 2.3.1 Front line workers must be well trained in meeting family needs and responsiveness to families has to be infused into the organizational culture.
 - 2.3.2 Service coordinators (case managers) need to receive in-service training from family members concerning wraparound and other appropriate services to support families.
 - 2.3.3 Service coordinators (case managers) need to pay particular attention to the voices of youth during in-service training.
- 2.4 Managed care systems must support the principles of wraparound (including "zero reject" and family-centered care) and cover the non-traditional services designed and delivered through this approach.

- 2.4.1 Managed care systems must ensure that a full array of community-based child and family support service options is developed before limitations on hospitalization and residential care are imposed or when capitation controls resources for mental health care.
- 2.4.2 Continuation of relationships family members have developed with mental health providers must be protected as managed care is introduced to replace current fee for service systems.
- 2.5 Managed care systems (both public and private) must have a comprehensive and easy to use appeals process for families to access when they disagree with the service plan or other decisions made by the managed care organization.

3 FINANCIAL CONSIDERATIONS

- 3.1 There needs to be money set aside by the managed care system to support and train family organizations as consumer-based entities that have a key role in monitoring of the managed care system, as well as to be involved in complaint review and policy development.
 - 3.1.1 These conditions need to be in the requests for applications or RFAs put out by the mental health authorities.
 - 3.1.2 Family organizations should receive funds from the managed care system to support advocacy for children with mental health needs, train providers and help families take responsibility for tracking down services and utilizing the system effectively.
- 3.2 Regardless of whether the managed care organization is a public or private entity, any cost savings should be reinvested in children's mental health services or the system of care.
- 3.3 Managed care systems need to ensure that families are not bearing the financial risk.
- 3.4 Managed care systems must cover early intervention services and other services designed to prevent escalation of mental health problems.
- 3.5 Managed care systems must establish and maintain mechanisms for insuring that flexible funds are available to support crisis intervention, respite care, wraparound and other non-traditional services designs and delivery strategies.
- 3.6 Resources must be provided to break down barriers to participation of families that lack ample financial resources. Lack of funds, credit cards or cash on hand, for transportation, child care and appropriate clothing are examples of common barriers that families face.

TWO PUBLICATIONS ON MANAGED CARE FOR CHILDREN

The Bazelon Center and the Federation for Families have collaborated on two guides about managed behavioral health care for children and youth—one for advocates and another for families. Here's how to order them.

A Family Advocate's Guide

Managed Behavioral Health Care for Children and Youth

Managed care is rapidly becoming the driving force for system reform in mental health, but the special needs of children and families are often not well addressed. This guide offers guiding principles on how managed care should work for children with mental, emotional or behavioral disorders. It includes a checklist of strategies to assure that state systems adhere to these principles. An appendix has handouts to copy and use to educate policymakers and managed care administrators.

☐ F-1: \$9.95, includes a copy of *Your Family and Managed Care* (call for discount on 10 or more).

Your Family and Managed Care

A guide for Families of Children with Mental, Emotional or Behavioral Disorders

A clearly written 16-page booklet explains the workings, advantages and pitfalls of managed care. Sections are titled: How Managed Care Can Improve Your Child's Access to Services; How Does Managed Care Control Costs? What You Can Do; What to Watch Out For; Family Report Card; and Checklist for a Managed Care Plan. Also has a one-page list of the goals of managed care for children with mental, emotional or behavioral disorders.

☐ F-2: Ordered separately, \$3.50 (call for discount on orders of more than 15 to the same address).

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